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Bloem, B. R., Henderson, E. J., Dorsey, E. R., Okun, M. S., Okubadejo, N., Chan, P., Andrejack, J., Darweesh, S. K. L., & Munneke, M. (2020). Integrated and patient-centred management of Parkinson's disease: a network model for reshaping chronic neurological care. *Lancet Neurology*, *19*(7), 623-634. https://doi.org/10.1016/S1474-4422(20)30064-8

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10.1016/S1474-4422(20)30064-8

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Integrated and patient-centred management of Parkinson's disease: a network model for reshaping chronic neurological care

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Word count: 4305
Key words: Parkinson disease; care; integrated; proactive; management; lifestyle; costs
Number of figures: 2
Number of panels: 5
Supplementary materials: 4

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Abstract

Chronic neurological diseases are the leading source of disability globally. Yet, our healthcare systems are not designed optimally to meet the needs of the many chronic neurological patients. Care is fragmented, with poor interdisciplinary collaboration and lack of timely access to services and therapies. Furthermore, care is typically reactive, and complex problems are managed inadequately due to lack of disease-specific expertise and insufficient use of non-pharmacological interventions. Treatment plans tend to focus on the disease rather than the individual living with it, and patients are insufficiently involved in clinical decision making. Utilising Parkinson's disease as a model condition, we illustrate an integrated care concept with a patient-centred perspective that includes evidence-based solutions to tackle the limitations of current healthcare delivery for people with chronic neurological conditions. We anticipate that this integrated care model will improve the quality of lives of patients and create an attractive working environment for professionals, whilst being affordable for future generations. **[151 words]**

Search strategy and selection criteria

We searched for publications on healthcare and neurological conditions (in particular Parkinson's disease) published in MEDLINE from 1 January 1990 to 28 January 2020, using comprehensive electronic search strategies combining MeSH and free text search terms "chronic", "care", "network", "patient-centeredness", "integrated", "multidisciplinary", "interdisciplinary", "technology", "health services", "wearable sensors", "telemedicine", "Parkinson disease" and "Parkinson's disease", without language restrictions. Selected articles were also obtained from the reference lists of papers identified by the PubMed search and from searches of the authors' own files. We included both original studies and viewpoints.

Background

Chronic neurological conditions are now the leading source of disability globally.[1] Because of a rapidly expanding ageing population, the worldwide prevalence and burden of chronic neurological diseases will rise further in the coming decades. To meet the needs of these many chronic neurological patients, an optimally performing healthcare system should reach the Quadruple Aim: enhancing patient experience, improving population health, reducing costs (these originally formed the Triple Aim)[2] and improving the work-life of clinicians.[3] However, recognition grows that our current healthcare system is not designed optimally to reach this Quadruple Aim. Indeed, the patient experience is far from optimal,[4] patients sustain avoidable disability, healthcare costs rise sharply and many clinicians face dissatisfaction or burnout.[5] Here, we review the challenges that current neurology care poses to patients, and introduce possible evidence-based solutions. We discuss how these solutions may be combined within a model of integrated care, which is defined as health services that are managed, discussed and delivered so that patients can make various health- and disease-related choices according to their needs throughout the life course.[6] This integrated model takes a patient-centred approach and would be tailored around helping chronic neurological patients to minimize the impact of their disease, and assists them in living independently at home, aiming to prevent escalation to more expensive institutionalised care (Figure 1). We illustrate our vision by using Parkinson's disease (PD) as a "model condition" for many other chronic neurological disorders (Panel 1), assuming that any successes obtained by improving the care for people with PD may be extended to other chronic neurological disorders. The model mostly entails solutions that are universally applicable (i.e. across a wide range of different chronic disorders) and that are at present largely restricted to specific health systems, such as middle- or high-income countries or public insurance-based healthcare systems.

Challenges and solutions for healthcare

Several barriers in today's healthcare hamper us from reaching the Quadruple Aim (Supplement A). We next discuss some solutions that can help to make care better equipped to overcome these barriers (Panel 2).

Care delivery close to home

Currently, chronic neurology care is delivered mainly in hospitals that are designed primarily for patients with acute diseases. Accessibility is limited for those living at greater distances.[57] Furthermore, medical decisions are based almost exclusively on periodic in-clinic evaluations, but such "snapshots" cannot capture the actual impact on the patient's functioning in their own home environment. An important aim is therefore to migrate neurological care away from medical centres, back into the patient's own home environment.[57] Being able to monitor and treat people at home is not only a service to patients, but also leads to more relevant insights, better care, and lower cost. Consequently, a patient's home could be considered a "Homespital" where some tasks currently performed within hospitals could be implemented.[58] We consider two important developments: first, the importance of assessing patients during their normal activities and functions; second, the value of delivering interventions as close to home as possible. New developments in the field of digitised health will be greatly supportive here (Supplement B). Remote monitoring can help to obviate unnecessary routine consultations among those doing well, while helping to identify those patients requiring medical attention. When care is required, the default should be to deliver care close to the patient's home whenever possible, and only within institutions when necessary.

Patient empowerment and self-management

Patients demand more empowerment than they currently receive. Against their wishes,[4,59] most patients are not well-informed about PD and are not counselled adequately to cope with the consequences. Therefore, a second goal is to shift from paternalistic care–led by healthcare professionals–to "participatory health", with equality in attitude towards complementary contributions of patients, carers and professionals. The focus should be on self-management by well-informed, empowered patients, with involvement of professional support when needed. The premise is that empowered patients will be less anxious, experience a better quality of life and are less likely to seek medical support, thus helping to reduce healthcare costs. This development fits with a new definition of "health", which is no longer described as the complete absence of any physical, mental or social unwell being, but rather as the ability to adapt and self-manage.[22]

Patients can be empowered in various ways (Panel 2). Adequate patient counselling is essential, yet patients generally feel uninformed.[4,59] Patient education must extend beyond information about the neurological condition or its management, and lifestyle advice should be part of counselling by healthcare professionals, irrespective of the health system they work in.

An important part of patient empowerment is introducing tools for shared decision making, allowing patients and carers to participate in making optimal treatment decisions, tailored to their specific situation. Formal procedures exist to develop validated shared decision tools, allowing patients to make weighed decisions based on reliable information about e.g. treatment effects or risk of adverse effects. Shared decision tools are already available for several key choices in PD management (Panel 2). Both patient and clinicians feel that use of Patient Reported Outcome Measures (PROMS) can help to support the shared decision process during consultations, although patients may need training to interpret the information correctly.[60] Involving patients in developing these instruments boosts face validity and increases their potential to reflect outcomes that are important to patients.[61] Achieving shared decision making should be a universal priority among healthcare professionals. However, much work remains to be done: a European survey indicated that many persons with PD feel insufficiently involved when it comes to making important treatment decisions.[62]

Patient empowerment also implies caring for the individual's entire environment, with specific emphasis on immediate carers. Caring for people with PD is associated with high burden, negatively impacts well-being and is associated with depression[63] and increased mortality risk.[64] Other psychological impacts include social isolation, loss of self-identity, feelings of helplessness and lack of control.[65] Carers often have their own healthcare needs and this, coupled with the physical and economic burden of caring, frequently precipitates inpatient admissions for patients who can no longer be cared for at home. Taken together, this is ample reason to consider not just the patient, but also the immediate carers.

Proactive and timely care

Current care is mainly reactive, focusing on tackling problems when they arise. This causes unnecessary burden for patients and leads to costly hospital admissions, many of which seem preventable. Optimal care involves not just responding to problems expressed by patients, but also adopting a proactive approach, aiming to detect early warning signs that may herald the onset of more debilitating (and costly) problems. Persons with PD are more likely to be admitted than their peers, disease progression being associated with unplanned hospital admissions.[66,67] Early recognition of patients at risk of admission

affords an opportunity to intervene. One example is timely detection of near-falls, which typically precede the onset of falls and fall-related injuries–the latter being a major cost driver in Parkinson care.[68] Rather than waiting for injuries to occur, preventive measures can be taken, including medication adjustments, specialized physiotherapy, and optimization of the home environment to minimize the risk of falling.[69]

Proactive care becomes increasingly relevant in older patients with PD with neuropsychiatric manifestations, including apathy or dementia, who are not well-positioned to assume a proactive role themselves. Case management serves a critical function to proactively identify these vulnerable patients. This may pre-emptively optimise their physiology and environment to minimise the risk of avoidable complications and prevent admission to hospital and care facilities. Yet, a reality is that hospital visits for complex patients can never be fully prevented.[66] [67]As inpatients, they have a longer length of stay than age-matched controls, with more deconditioning, loss of confidence and exposure to iatrogenic risks (such as hospital-related infection). They are also less likely to return to their normal place of residence and to have higher in-hospital mortality.[70] Delays in receiving 'medication on time' can further exacerbate problems of reduced mobility, swallowing difficulty and falls. Inpatient care should therefore be optimised to minimise the risk of these complications, including education of ward nurses on the importance of 'medication on time'. Specific measures include early PD specialist review to optimise medication, also for admissions to general wards.[71,72] This process should be supported by early flagging in electronic medical records, to alert a dedicated inpatient team that someone with PD has been admitted. Unpublished experience at Struthers Parkinson's Centre in the U.S. shows that such electronic flagging can markedly improve the timing of levodopa administrations and minimize missed doses in the hospital and emergency centre (Nance M. & Wielinski C., personal communication). This example illustrates how proactive screening can be facilitated by developments in digital health (Supplement B). Digital health could improve the quality of care, and potentially save costs, e.g. because proactive monitoring can prevent complications. However, the evidence for this remains limited, also when it comes to demonstrating beneficial effects on patient outcomes.

Precision medicine

Current treatments typically follow a "one-size-fits-all" approach, but there is an urgent need for development of personalised "precision" approaches, with care tailored to each patient's unique profile and personal needs. Therefore, a further key element is delivery of care according to each patient's unique sociodemographic, disease-specific and genetic factors, considered in tandem with their personal objectives and goals. Current scientific evidence, especially insights derived from controlled clinical trials, is imperfect in this regard, because the insights are based on relatively small and often selected study populations, with brief follow-up periods, making it difficult to translate the outcome to the care for individual patients in everyday practice. This applies particularly to specific underserved subgroups, caused by issues related to age,[73] gender,[26,74] racial[27-30] or cultural differences.[31,32]

Realisation of personalised medicine will greatly benefit from developments in the fields of "big data" and artificial intelligence,[40,41] where insights derived from much larger and unselected real-life populations, or from smaller groups of deeply phenotyped patients, can lead to development of fine-grained personal disease profiles that better represent the full complexity of individual patients. Such knowledge will allow clinicians to offer patients more detailed prognostic information based on personalized profiling, and to tailor their treatment advice to the unique profiles of their patients, which is particularly important for a disorder characterized by significant heterogeneity like PD.[42] The first positive experiences in the PD field

are emerging, mainly in establishing more refined prognosticators for specific endpoints at the group level, but reliable individual predictors have yet to be identified.[75-80] Importantly, big data approaches do not intend to replace existing information resources, but can rather act as a fourth and complimentary source of information in clinical decision making, next to scientific evidence, professional expertise, and the personal needs and preferences of patients. Combining the strength of all four information sources then leads to a process of 'quadruple decision making'.[81]

Specialist care and professional training

Management of chronic neurological conditions like PD has transformed into a complex, highly specialised field of medicine, calling for expert skills to ensure that patients receive optimal care, in accordance with the latest scientific evidence. Such specialised professionals are more likely to adhere to professional guidelines, and are better aware of what fellow professionals can contribute to care.[44] Trainings are delivered best to multidisciplinary teams, which improves PD-specific knowledge and leads to a better understanding of the role of other disciplines.[46] Allocating care preferentially to allied health professionals who have specialised in PD management is associated with better patient outcomes and lower costs in the Netherlands (ParkinsonNet model of care–Panel 3).[45,82] There are also successful examples in other areas of neurology and other fields of medicine, where specialisation was associated with better care, better patient health and cost savings.[83,84] Medical societies should always be involved in ascertaining the quality and nationwide implementation of the educational programs. For example, all training programs delivered by ParkinsonNet are done according to guidelines that have been ratified by the corresponding national medical societies. The Dutch experience indicates that the costs of such educational programs are offset by subsequent cost savings.[44]

Professional training may further help improve the quality of care for persons with PD in nursing homes, where both undertreatment with Parkinson medication and overtreatment with sedatives are common.[85] Another area of largely unmet need relates to end-of-life issues and palliative care interventions, which are traditionally equated with cancer management. Persons with PD also experience moderate palliative care needs,[86] but palliation is presently unavailable for most patients.[50,51] Recent work demonstrated that a one-year multidisciplinary palliative care program improved quality of life for patients with moderate palliative care needs,[87] emphasising the importance of training professionals to recognise and manage palliative care needs as part of integrated PD management.[88]

Finally, professional training may help to create a positive healthcare engagement for professionals, and enhance their experience of delivering care. Complex and debilitating neurological conditions such as PD can be alarming to inexperienced clinicians, but can be gratifying when their knowledge is adequate, and when clinicians accumulate greater experience by managing a high case load of patients with comparable health issues.[89] Enhancing the work-life of clinicians thus helps to achieve the Quadruple Aim by reducing burnout,[3] and possibly by motivating students to opt for a future career in medicine.

Care management

Current care is fragmented across different healthcare providers and organisations, leading to a waste of resources. Unsurprisingly, people with PD–when asked to identify their top priorities for healthcare improvement–identify access to a single point of access (personal care manager) as their most urgent need.[4] The personal care manager can act as a single point of access who can immediately answer questions, or triage the issue accordingly.[4] It is neither feasible nor cost-effective to place the movement

disorder specialist in this role. The reality is that there is already a shortage of specialist clinicians for a fast-growing Parkinson population.[7,90] Consequently, waiting lists are long, and movement disorder specialists have limited time to see their patients. The Parkinson nurse is an excellent candidate to fulfil this role of being the first point of access for patient queries, with several specific tasks: triage, dedicated referral, and care coordination (Supplement C). Nurses in this role may be based in community hospitals–acting as a personal care manager–but in less densely populated areas, nurses could also deliver services from a remote service desk (telephone call centre), acting as telehealth assistants. Such a model is recommended and partially in place in the UK,[52] although many areas lack sufficient numbers of specialised nurses to deliver ready access to all patients, and to fully adopt the role as personal care manager.

An important part of care coordination is to establish links between PD-specialists and generalists working in the community, including general practitioners who are optimally positioned to manage comorbidities and polypharmacy within the wider social context, in relation to the domestic situation.[53] Increasing PD-specific knowledge amongst general practitioners will augment their confidence in caring for patients with complex neurological illnesses and strengthen collaborative links with movement disorder specialists.[53] To achieve this, general practitioners should be provided with easy access to a specialised network professional when in need of referral for a PD-specific health issue. Furthermore, general neurologists working in community hospitals can deliver higher-quality care for people with PD when supported by a remote PD-expert via telemedicine (peer-to-peer consultations). This approach previously contributed to more accurate clinical decision making in the field of acute stroke treatment.[54]

Delivery of integrated care

Each of the aforementioned solutions, when delivered in isolation, will help to improve the quality of care for patients with neurological illnesses. However, we anticipate that care delivery can be optimised further by seamlessly connecting the layers of healthcare and bundling all solutions into an integrated network, across both professional disciplines and different healthcare settings.[56] Such an integrated model is referred to as population health management, where responsibility is taken for an entire specific population, including cross-sector collaboration, coordination with community services (also the social domain, e.g. ascertaining adequate housing circumstances) and non-clinical interventions (e.g. healthier lifestyle).[2,91] There is some initial evidence to suggest that this approach leads to better outcomes, while overall healthcare spending remains the same.[91]

A “home-hub-and-spoke” model is one way of structuring care services for a whole population (Figure 2). The patient’s own home represents the first of three constituents; efforts directed here include patient education, promotion of self-management, and home-based monitoring. The movement disorder specialist in a community hospital, combined with specialised allied health professionals in the regional community, jointly form the second constituent (“spoke”). Many services can be offered here. The role of the third part–an academic “hub”–is not in physically seeing many patients, but in adding value to the entire network, e.g. via peer-to-peer support for multiple spokes, educating patients and professionals, guideline development, and research. This hub may be located geographically close to its surrounding spokes, although many supportive services can be offered remotely via telemedicine–thus creating a virtual hub.

The need for integrated care increases when advanced and likely expensive new treatments become available, such as pharmacological and non-pharmacological disease-modifying strategies. In these situations, considerable PD-specific knowledge is required for optimal decision making. In the proposed model, regional movement disorders specialists would have a critical role in informing decisions, supported where necessary by expertise and infrastructure at the hub (peer-to-peer expertise via telemedicine would be appropriate for this). Such remote hub support could also support the diagnostic process (review of videotaped neurological exams), because the rate of diagnostic misclassification in early disease stages is higher among generalists than among experts.[92]

The experience with integrated care is thus far not unequivocally positive, although most studies suggest that reductions in hospital (re-)admissions and emergency department visits can be achieved.[56] Further work is now needed to demonstrate the actual value of integrated care for patients with neurological diseases. Additional research is also warranted on the implementation of the model in conditions where cognition is significantly affected, such as Alzheimer's disease or other primary dementias.

Financial considerations

The primary aim of integrated care should be an improved quality of life for patients with chronic neurological conditions, and a better population health. Cost containment is not a purpose in its own right,[91] although integrated care might reduce costs, which is one component of the Quadruple Aim (Figure 1).[3] Cost savings may result from greater efficiency of care, prevented disease complications and reductions in unplanned hospital admissions (Panel 4), although any cost savings are potentially offset by the necessary upfront investments in quality of integrated care.[91]

There is some evidence in the field of PD to support these assumptions. For example, various studies showed that professional specialisation, improved interdisciplinary collaboration and patient education–as achieved via the Dutch ParkinsonNet approach (Panel 3)–leads to considerable cost savings, via greater efficiency of care (specialised therapists provide substantially less treatment sessions) and fewer disease complications (injuries or pneumonia).[43-45,47] Taking the most conservative cost saving of $439 per patient,[93] the savings equated to around 5% of the expenditure on chronic Parkinson care in The Netherlands (about 20-30 million euros annually). It is conceivable that adding further elements to this approach–e.g. personalized care management–will lead to even greater cost savings. As such, integrated care models can help to ascertain an affordable care system for our future generations. Importantly, while this model for network-based allied healthcare was originally developed in The Netherlands, which has a public insurance-based healthcare system, it has subsequently been successfully transferred in healthcare systems that had a different infrastructure (e.g., Kaiser Permanente, an accountable care organisation in California).[94] We note that translation of this model and its possible implications for cost savings requires further study in other healthcare systems.

Challenges in rural and low-resource settings

Four decades after the WHO declared 'health for all' by the year 2000, international and even regional differences in quality of care for patients with chronic diseases remain stark. We realize that implementing an integrated model of care, or even elements thereof, will pose tremendous challenges in sparsely populated or economically less developed areas of the world. We therefore anticipate that the network by which integrated care is delivered will depend on local, regional or national circumstances, including the geographical spread of the population across urban and rural areas, and on physical

distances. In countries where healthcare delivery for people with PD is largely hospital-based or delivered across substantial distances, care models must be adapted. For example, introduction of network care in California pursued the concept of specialised professional education, but not for allied health therapists working in the community–as was feasibly done in a densely populated country such as the Netherlands–but rather by training hospital-based teams.[94] This approach, although different, also resulted in the desired concentration of care among specifically trained professionals,[94] which is a subsidiary intermediate for achieving good outcomes.[44]

The current and future provision of Parkinson's nurses, movement disorder specialists and multidisciplinary expertise will also impact on care structures. In countries such as the UK and the Netherlands, where the Parkinson's nurse specialist role is well-established and successful, nurses are based in both community and secondary care settings. However, most Parkinson's nurses in these countries work closely with movement disorder specialists who treat the same people with PD, suggesting that transference of this model may be challenging to countries where patients lack regular follow-up by a movement disorder specialist. For example, 33% of people with PD in the U.S. do not receive regular neurologist care, let alone movement disorder specialist care.[29]

Challenges will be even greater in in economically less developed areas of the world (Supplement D). Here, barriers relate to human resources (e.g. lack of sufficiently trained healthcare professionals), financial factors and cultural differences in leadership or accountability.[95] In many countries worldwide, numerous patients remain undiagnosed,[96] while essential medication such as levodopa is either poorly available or, even when offered, unaffordable for many.[31] Furthermore, people from several large regions (e.g. the Western Pacific) are underrepresented in healthcare innovation research, despite substantial variability in the clinical presentation and comorbidity profiles of PD patients across the world.[97] The role of telemedicine will become particularly important in combatting these challenges in both clinical care and research. In countries such as China, readily available app programs on mobile phones are already widely used among medical professional and patients for communication or consultations. A complimentary strategy would be to ensure that healthcare professionals in low-resource settings receive clinical decision support algorithms covering evidence-informed care. In the area of communicable diseases, this strategy substantially improved measures of population health, quality of care and effective use of healthcare services.[95]

Conclusions and future perspectives

Using PD as an exemplar condition, we have illustrated a model of care for patients with neurological conditions, including a patient-centred and proactive approach embedded within integrated networks where specifically trained professionals from multiple disciplines collaborate effectively (panel 5). We foresee an increasingly prominent and recognised role for specialised nurses, acting as personal care managers for individual patients and as care coordinators for the network. Part of this vision is supported by empirical evidence, albeit mainly for the separate components of the integrated approach. There are also striking lacunae in our knowledge, such as lack of scientific underpinning for the roles of Parkinson nurses. Future work must therefore gather further evidence, both for all separate components and their integration. A challenge here is that evaluations of such complex interventions require a spectrum of approaches to provide robust evidence. Alongside randomised clinical trials, this could include additional methodologies such as observational studies with analyses of medical claims data–comparing regions with integrated care versus geographically separated regions with care as usual.[98]

While most solutions proposed in the model could be readily implemented across various health systems and patient groups, including those in low-resource settings or areas where distances are substantial, other solutions may not be universally applicable. In particular, the feasibility of leveraging novel technological developments may in the near future be limited to high- and middle-income countries. Beyond the very short-term, however, technological developments may also become available to people with PD in low-income countries, given the remarkable recent rise in smartphone ownership across impoverished regions; e.g., in Sub-Saharan Africa, smartphone ownership rose from 15% in 2014 to 33% in 2017.[102]

We anticipate that patients with other chronic and complex progressive neurological conditions like dystonia or neuromuscular diseases, or those with a more paroxysmal or fluctuating character like epilepsy or relapsing-remitting multiple sclerosis, also deserve an approach of networked care with a patient-centred, proactive methodology delivered by specialised professionals treating a high case load. Modifications in care delivery may be required, depending on the nature and prevalence of each condition and on specific patient needs. For example, considerably fewer professionals have to be trained for rare disorders such as Huntington disease, so concentration of expertise within a limited number of expert centres makes sense, in contrast to PD where community-based networks seem effective. The knowledge in some of these areas of neurology is growing, as exemplified by positive experiences with network care for e.g. patients with Alzheimer disease.[9] A key point will be to learn from contrasts between different networks, so the best of all worlds can be synthesised into an optimised care model. From a population health management perspective, it might be beneficial to concentrate expertise around a number of comparable chronic progressive neurological disorders within bundled specialised networks, which are characterized by a patient-centred, proactive methodology delivered by specialised professionals treating a high case load of comparable chronic progressive neurological disorders, including selected outreach clinics with connection to hubs specializing in each of the subspecialty areas. Bundled specialised networks include selected outreach clinics with connection to hubs specializing in each of the subspecialty areas. We anticipate that research on bundled specialised networks will rapidly increase in the next years. We therefore extend an open invitation to colleagues from other fields to share their experiences, so that all our patients can benefit.

Contributors

BRB prepared the first draft of the manuscript. The remaining authors provided feedback on this first draft. EH provided specific contributions to the sections on nursing home care palliative care and care management; MO, SKLD, PC and MM on the integrated care model; ERD on the sections on remote monitoring; NO and PC on the section on underserved countries; JA offered the patient perspective for all sections of the manuscript. All authors approved the final version of the manuscript.

Acknowledgments

The Centre of Expertise for Parkinson & Movement Disorders was supported by a centre of excellence grant of the Parkinson Foundation. The contributions by Prof. Bas Bloem, Dr. Emily Henderson, Dr. Sirwan Darweesh and Dr. Marten Munneke are part of the collaborative PRIME project, which is financed by the Gatsby Foundation and the Dutch Ministry of Economic Affairs by means of the PPP Allowance made available by the Top Sector Life Sciences & Health to stimulate public-private partnerships.

Declarations of interest

Prof. Bloem currently serves as co-Editor in Chief for the *Journal of Parkinson's disease*, serves on the editorial of *Practical Neurology* and *Digital Biomarkers*, has received honoraria from serving on the scientific advisory board for Abbvie, Biogen and UCB, has received fees for speaking at conferences from AbbVie, Zambon, Roche, GE Healthcare and Bial, and has received research support from the Netherlands Organization for Scientific Research, the Michael J Fox Foundation, UCB, Abbvie, the Stichting Parkinson Fonds, the Hersenstichting Nederland, the Parkinson's Foundation, Verily Life Sciences, Horizon 2020 and the Parkinson Vereniging.

Dr. Emily Henderson received funding from the National Institute of Health Technology (NIHR), the Gatsby Foundation and Parkinson's UK; received fees for speaking and consultancy from Profile pharma Medicys and Luye; and received travel support from Bial Abbvie and Ever pharma.

Dr. Michael Okun serves as a consultant for the Parkinson's Foundation, and has received research grants from NIH, Parkinson's Foundation, the Michael J. Fox Foundation, the Parkinson Alliance, Smallwood Foundation, the Bachmann-Strauss Foundation, the Tourette Syndrome Association, and the UF Foundation. Dr. Okun's DBS research is supported by: R01 NR014852 and R01NS096008. Dr. Okun has received royalties for publications with Demos, Manson, Amazon, Smashwords, Books4Patients, Perseus, Robert Rose, Oxford and Cambridge (movement disorders books). Dr. Okun is an associate editor for New England Journal of Medicine Journal Watch Neurology. Dr. Okun has participated in CME and educational activities on movement disorders sponsored by the Academy for Healthcare Learning, PeerView, Prime, QuantiaMD, WebMD/Medscape, Medicus, MedNet, Einstein, MedNet, Henry Stewart, American Academy of Neurology, Movement Disorders Society and by Vanderbilt University. The institution and not Dr. Okun receives grants from Medtronic, Abbvie, Abbott and Allergan and the PI has no financial interest in these grants. Dr. Okun has participated as a site PI and/or co-I for several NIH, foundation, and industry sponsored trials over the years but has not received honoraria. Research projects at the University of Florida receive device and drug donations.

Prof. E. Ray Dorsey is a medical advisor to and holds stock options in Grand Rounds (https://grandrounds.com/). Grand Rounds' experts provide a second opinion on the diagnosis and management of health care conditions (e.g., low back pain, cancer) of employees generally of large corporations. These second opinions are usually provided after review of medical records and addressing written questions of patients. This model is not discussed in the paper. Prof. Dorsey has also received honoraria for speaking at American Academy of Neurology courses; received compensation for consulting activities from 23andMe, Clintrex, GlaxoSmithKline, Lundbeck, MC10, MedAvante, Medico Legal services, the National Institute of Neurological Disorders and Stroke, Shire, Teva, and UCB; research support from AMC Health, Burroughs Wellcome Fund, Davis Phinney Foundation, Duke University, GlaxoSmithKline, Great Lakes Neurotechnologies, Greater Rochester Health Foundation, Huntington Study Group, Michael J. Fox Foundation, National Science Foundation, Patient-Centered Outcomes Research Institute, Prana Biotechnology, Raptor Pharmaceuticals, Roche, Saffra Foundation, University of California Irvine.

Prof. Piu Chan has received honoraria from serving on the scientific advisory board for Lundbeck, Teva, and Green Valley, has received fees for speaking at conferences from Roche, Lundbeck, Sanofi, Eisai, Green Valley, Luye, GlaxoSmithKline, Medtronic and Berlinger-Ingerham; has received research support from the Chinese Organizations for Scientific Research, and the Michael J Fox Foundation.

Prof. Njideka Okubadejo, Mr. John Andrejack, Dr. Sirwan Darweesh and Dr. Marten Munneke have no conflicts of interest to report.

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Panel 1. Parkinson's disease as a model condition.

We regard Parkinson's disease as an ideal "model condition" for many other chronic neurological disorders, for various reasons: (a) the clinical phenotype encompasses a wide range of motor as well as non-motor features, including cognitive decline, autonomic failure and neuropsychiatric features; (b) optimal Parkinson care requires involvement of multiple (over 20 different) professional disciplines, who work in different healthcare settings, including the community, regional hospitals and specialised clinics; (c) management is multimodal, involving complex pharmacotherapy, neurosurgical procedures, and various non-pharmacological interventions; (d) the disease duration is long, spanning up to decades for affected patients, plus a presumably lengthy prodromal phase; and (e) the disease is common, with an incidence and prevalence that are rising due to demographic changes and possibly other factors.[7]

Panel 2. Challenges and suggested solutions to improve the management of patients with chronic neurological conditions like PD. For each proposed solution, we provide supportive evidence, capitalizing not only on the experience in the field of PD, but also on knowledge obtained for other conditions such as dementia[8,9] and other fields of medicine. The far-right column indicates whether a solution is part of a "minimum standard" that might be more readily available for wider scaling across other countries, healthcare systems or areas of medicine; no formal specific criteria for such a "minimum standard" have been defined to date, so the suggestions offered here can only be used to offer some global guidance.

Challenges	Possible solutions	Specific example(s)	Minimum standard
1. To organize care close to home	• Remote/ambulatory monitoring	• Passive monitoring of falls in home environment[10,11] • Passive monitoring using mobile health technologies (e.g. electronic device typing)[12,13] • Active monitoring (predefined tasks using smartphone to assess postural tremor or responsiveness to changes with medication[14,15]) • Other[16]	• No
	• Online communication	• Use online communities to support patient empowerment[17]	• No
	• Virtual or physical home visits	• Telemedicine visits by neurologists[18] • Interdisciplinary plan including home visits[19,20] • Secure video-conferencing[18,21]	• Yes
2. To inform patients and carers, and support self-management	• Focus on ability to adapt and self-manage	• Education on daily life management[22,23]	• Yes
	• Promoting healthy lifestyle	• Healthy diet[33] • Exercise[34-36]	• Yes
	• Support for working capacity	• Education on strategies and techniques to counteracting symptoms of PD, enabling longer workforce participation[37]	• Yes
	• Shared decision making	• Shared decision tools for making informed choice between available options for continuous dopaminergic stimulation (deep brain stimulation, intraduodenal levodopa, apomorphine)[38]	• Yes
	• Caregiver support	• Peer-to-peer caregiver education[39]	• Yes

3. To manage care proactively	• Timely identification of specific complications that – if left untreated – may lead to greater handicap and costly admissions	• Active screening for precipitants of hospital admission such as near-falls	• Yes
4. To provide personalized "precision" medicine	• Focus on individual patient priorities	• Consider striking difference between men and women in clinical presentation, treatment response and healthcare utilisation (e.g., brain surgery for PD)[24-26] • Consider racial[27-30] or cultural differences[31,32]	• Yes
	• Big data and artificial intelligence	• Enable personalized profiling and individualized prognostic or treatment advice[40-42]	• No
5. To enable access to appropriate care	• Parkinson-specific specialisation for all professional disciplines involved in Parkinson care, according to evidence-based guidelines	• Training of commonly engaged disciplines, such allied health professionals or specialised nurses[43-48] • Training of less commonly recognised disciplines such as dentist or pulmonologist[49] • Include nursing home staff and clinicians involved in advanced care planning (issues at the end-of-life, palliative care)[50,51]	• Yes
	• Concentration of care among trained experts (increase case load)	• Dutch ParkinsonNet approach[44]	• Yes
	• Organising peer-to-peer networking	• Implement interprofessional education for healthcare professionals on evidence-based PD practices and working effectively in teams[46]	• Yes
6. Care management	• Coordination of care	• Employ personal care managers to coordinate care for people with PD[52]	• Yes
	• Establish links between PD-specialists and generalists working in the community	• Increase PD-specific knowledge amongst general practitioners[53]	• Yes
	• Telemedicine (peer-to-peer consultations)	• More accurate clinical decision making in the field of acute stroke[54]	• No
7. To deliver integrated care and	• Breach silos by connecting all layers of healthcare and bundle	• Some examples in the field of dementia[55]	• Yes

continuity of care	into model of integrated network care, both across professional disciplines and across all echelons	• Scarce examples available outside the field of neurology;[56] models yet to be implemented for chronic neurological patients	

Panel 3. Key elements and outcomes of the Dutch ParkinsonNet model of care.

This model was introduced in 2004 in the Netherlands as an innovative treatment concept for patients with PD. Specifically, ParkinsonNet consists of regional community-based networks that encompass a restricted number of dedicated allied health therapists who have been trained specifically according to evidence-based guidelines. Key elements of the model are described in detail elsewhere[44] and are summarised below. ParkinsonNet has reached full national coverage in the Netherlands, and currently includes 74 regional sub-networks with a total of 3,400 specifically trained healthcare professionals, including—among others—physiotherapists, occupational therapists, speech-langue therapists, dieticians, and Parkinson nurses. Of note, ParkinsonNet is embedded within a not-for-profit organisation.

Component	Specification
*Guidelines**	• Monodisciplinary—for physiotherapy, speech-language therapy, occupational therapy, dietary issues, and nursing home care • Multidisciplinary—includes a consensus-based model for regional and transmural organisation of multidisciplinary care
Preferred referral	• Patients and physicians preferentially funnel their referrals towards ParkinsonNet experts to increase their caseload (using standardized referral forms with referral criteria)
Education	• Baseline training of participants according to evidence-based guidelines (4 days) • Learning on the job: increase experience by treating many patients • Continuous interaction and information exchange between participants through an annual national conference, regional interdisciplinary meetings (at least twice a year), and participation in web-based national and regional communities
Information technology platform	• Informative website (www.ParkinsonNet.nl) • Healthcare search engine (www.ParkinsonZorgzoeker.nl) • Web-based communities for patients and professionals (www.parkinsonconnect.nl)
Selection and re-certification	• Inclusion of motivated and specifically trained healthcare providers only. Every two years a mandatory re-certification is required based on quality of care criteria
Commitment	• Members agree to work according to treatment guidelines and to collaborate with other professionals in multidisciplinary teams.
Transparency about quality of services and health outcomes	• Outcomes, costs and average caseloads at the regional level published in the Parkinson Atlas (www.ParkinsonAtlas.nl)
Patient-centred approach	• Various approaches, including use of guidelines for patients, web-based communities for patients and web-based informative television program for patients (www.ParkinsonTV.nl)

*Evidence-based recommendations and consensus-based statements (www.parkinsonnet.com/guidelines)

Panel 4. Expected cost savings from an integrated care approach.

Mechanism
Improved quality and efficiency of diagnosis (less demand for ancillary testing)
Fewer outpatient visits: - More self-management - Healthier lifestyle - Optimally timed consultations because of remote monitoring - Telemedicine visits instead of physical visits to the hospital
Fewer inpatient admissions: - Prevented disease complications including fractures - Fewer medication errors
Substitution of care: - Nurse-led care reduces pressure on more expensive evaluations by movement disorder specialists
Optimal use of integrated multidisciplinary care: - Personal care manager ascertains timely referral to specialized professionals
Seamless organisation of the entire healthcare chain: - Less financial waste caused by transitions between echelons

Panel 5. Take-home messages.

- Whenever possible, care should be delivered, where possible within or in proximity to the patient's own home environment, both in terms of monitoring and care delivery.[57]
- Educating patients, supports them in self-management, relieves anxiety and alleviates pressure on the medical system.[4,22,59-65]
- The approach to neurology care should be proactive instead of reactive, thereby preventing disease burden and avoiding escalation to more expensive care (including avoidance of unplanned admissions).[66-72]
- Proactive care can be supported by remote monitoring using sensors and e-diaries, allowing for timely detection of medical problems before they derail.[99-101]
- Care should be delivered according to each patient's unique sociodemographic, disease-specific and genetic factors, considered in tandem with their personal objectives and goals, following personalised "precision" approaches.[26-32,40-42,73-81]
- Management of complex neurological conditions such as PD is beyond the expertise of generalists *alone*. There is actually a very important role for generalists in the management of persons with PD. In addition, patients benefit from having access to specialised professionals who attract a high case load of patients with a particular neurological condition.[44-46,50,51,82-89]
- Patients should have easy access to a single point of access (personal care manager) who can directly answer simple questions, refer patients to appropriate colleagues, and coordinate the multidisciplinary team advice.[4,7,52-54,90]
- Care delivery can be optimised further by seamlessly connecting the layers of healthcare and bundling all solutions into an integrated network, across both professional disciplines and different healthcare settings. [2,56,91,92]

Figure 1. Challenges and strategies for achieving the quadruple aim
The central goal of healthcare is to reach the Quadruple Aim (central circle). Six important challenges must be addressed in order to reach this goal (second circle). We also identify four main strategies that can help to address this series of challenges (outer circle). The interplay between these four strategies and six challenges in reaching the Quadruple Aim is complex and multifaceted. For example, patient empowerment helps to achieve a more personalized care delivery, facilitates care delivery close to home and makes care timelier, with an improved patient experience, improved health outcomes and reduced costs as important results. Similarly, professional empowerment ascertains that patients receive appropriate care, but well-trained clinicians are likely also better able to deploy precision medicine approaches. Each of the four strategies is facilitated by modern technological solutions (Supplement B).

Figure 2. The “home-hub-and-spoke” model

A. Illustration of how a centre of expertise (the hub – services shown in blue) can be coupled to a single spoke (services shown in red), consisting of a neighbouring community hospital (where regional care is delivered by Parkinson’s specialist doctors), a Parkinson nurse (acting as personal care manager) and regional community-based professionals. Specific services offered include: (1) remote home-based monitoring and self-management by patients; (2) personalized care management; (3) a specialised regional care team, including facilities for inpatient and outpatient rehabilitation, and nursing homes with trained staff; (4) remote peer-to-peer support offered by a centre of expertise, with the option to physically see patients with specific health issues (complex or expensive ancillary testing; advanced treatments); and (5) centralised educational and supportive resources for both patients and professionals (services shown in green). **B.** One centre of expertise can support many surrounding community hospitals (multiple spokes). The Parkinson nurses working in the various spokes could collectively form a virtual service desk, to provide easy access for Parkinson patients.

Supplement A. Barriers to reaching the Quadruple Aim.

Several important barriers in today's healthcare that hamper us from reaching the Quadruple Aim. These are visible even in high-income countries such as the U.S. or United Kingdom, with even worse conditions in lower income countries.[31,103] The inadequacies of care exist worldwide in spite of different models of healthcare and differences in funding. Together, these shortcomings lead to avoidable disability and unnecessarily high costs.

Fragmentation of care: • Poor interdisciplinary collaboration and disconnected monodisciplinary therapies • Numerous barriers between different healthcare settings • Difficult, delayed and greatly variable access to services and therapies[29,30] • Traditional hierarchical approach
Reactive approach: • Focusing on repairing problems after they have arisen *
Inability to manage complex problems: • Lack of disease-specific expertise among many clinicians
Predominantly physician-driven care: • Primary focus on medical management (pharmacotherapy, neurosurgery), with less attention to non-pharmacological interventions, and even less to lifestyle or social issues • Lack of patient involvement in decision making
Emphasis on institutionalized care: • Outpatient visits inadequate reflection of problems in daily living[57] • Inpatient visits often associated with poor services and outcomes[66,104]
Disease-centred care: • One-size-fits-all approach • Emphasis on protocols that are informed by averaged group results from trials.

* For example, in the UK, unplanned hospital admissions among persons with PD are often related to falls and to urinary tract infections, some of which may be anticipated and proactively managed. In the U.S., 88% of personal healthcare expenditures are devoted to hospital or nursing home care, whereas only 7% is spent on ambulatory care[105]–where these admissions could perhaps be avoided through timely recognition and management of PD-specific complications.[106]

Supplement B. Digitised health as supportive tool to enable integrated care.

Many of the integrated care solutions proposed here can be supported by new developments in the field of digitised health and technology-enabled "individualization", not as a goal in its own right, but as a supportive tool to make the proposed interventions more effective, customer-friendly, timely and cheaper. We distinguish several important digital enablers:

- **Ambulatory real-life monitoring**, using sensors–worn on the body,[13,16] intelligent domotics incorporated into the patient's house (i.e. smart homes with embedded sensors, for detecting e.g. daily mobility, or falls)[107,108] or analysing the usage of common appliances such keyboard typing behaviour[12]. These approaches hold great promise to assess patients in their own environment. Specific symptoms such as tremor seem very "measurable", but others with a more complex symptomatology such as dyskinesias in PD, are less straightforward to capture. Monitoring can be *passive* (occurring in the background) or *active* (asking patients to complete scheduled tasks at fixed intervals). Specific examples of both types of monitoring are presented in Panel 2. Many issues remain, including the need to optimise compliance with technical devices, particularly among older people and those with cognitive impairment; and having a readily available helpdesk strategy.[11] Patients themselves are open to self-monitoring, although a balance must be struck between the burden (time and energy spent) and benefits (great knowledge and self-efficacy).[109] Another challenge is the need to validate the sensor's algorithms not just in the laboratory, but also in real-life settings where patients can behave very differently.[110] Finally, sensors are likely most helpful to monitor motor symptoms, but the many non-motor symptoms (e.g. cognitive decline, autonomic failure) are at least as important to patients.[111] Development of a reliable e-diary could serve this purpose.[112]
- **Online communication platforms**, enabling easy patient access to care, and facilitating interdisciplinary communication and collaboration between different professionals, and between patients and professionals.[17,21] This includes the ability to easily exchange relevant medical information and to synchronize the patient's healthcare plan, to promote communication between patients and their healthcare team and to facilitate the exchange of knowledge.
- New developments in **telemedicine** may allow professionals to pay a virtual home visit via secure videoconferencing.[21] This is important where travel distances are long or travel burden is high or because driving behaviour has become unsafe for people with neurological disorders such as PD.[113] A next step is to develop this telemedicine approach for other disciplines, such as specialised nurses or allied health therapists, thus creating a concept of "tele-rehabilitation". Recent work has shown the feasibility of this approach for people with stroke, showing that activity-based training was as effective when delivered via telemedicine as compared to an in-clinic program.[114] Safety issues must be addressed, e.g. the risk of falling when physiotherapists deliver balance training or exercise programs remotely. Early studies formally assessing the utility of home visits from the multidisciplinary team have showed promise.[19]
- **Big data and artificial intelligence**, for personalized profiling and individualized prognostic or treatment advice.[40,41,90]

Current evidence on the role of digital health in the care for patients with PD

Prior research mostly focused on developing reliable algorithms, testing their face validity relative to current clinical measures, or demonstrating the feasibility of introducing technological innovations to a typically elderly population, including persons with cognitive decline, reduced dexterity (hampering adequate manipulation of devices) or simply lack of appetite for technological innovations.[11,110,115,116] Small pilot studies using remote monitoring with wearable sensors suggested some positive effects on clinical decision-making and reasonable correlations with motor symptoms of PD.[99-101] The costs of many technological solutions are likely low (certainly with bring-your-own-device solutions, such as a person's own smartphone), but whether these upfront investments are outweighed by subsequent health benefits or cost savings remains unclear. One study provided class III evidence that a telemedicine approach–offering neurology services via video conferences–was feasible and resulted in health outcomes comparable to regular outpatient visits, but with greater efficiency and convenience for patients (no time wasted on traveling or waiting rooms).[18] How this translated into possible cost savings was unclear. Further work remains needed to establish the

cost-effectiveness of the whole gamut of digital health solutions. Furthermore, reliable algorithms must be developed that can trigger an intervention by healthcare professionals when a dangerous situation or high-risk trait is detected automatically. This issue was recently addressed in a study on passive monitoring of falls that occurred in the own home environment of persons with PD.[11] In that study, fall events were automatically detected by a wearable sensor, and all falls were confirmed by an immediate follow-up call (i.e. there were no false-positive events). The feasibility of that approach is conditional on the availability of support personnel to follow-up with an immediate call, aiming to send staff to the patients' home to assist those unable to rise from the floor independently. Future developments could focus on developing reliable algorithms for body-worn or domestic sensors to detect other relevant events that are difficult to capture during brief outpatient visits, such as complex response fluctuations to dopaminergic medication or gradual decreases in physical activity. The validity of such algorithms must be demonstrated not just in controlled laboratory conditions, but also in daily-living cicrumstances.[110] Importantly, before replacing components of usual care, it is essential that digital innovations are studied as carefully designed add-on interventions in real-life settings. Finally, we should point out that the transition to telemedicine-based solutions will take time, even for seemingly straightforward errands such as refilling prescription medication, which in countries like China currently requires patients to visit the hospital.

Supplement C. The role of Parkinson nurses in care management.

Nurses can facilitate the actual implementation of the management plan which can prove particularly challenging to people with PD who are affected by dysexecutive problems. Evidence suggests that most recommendations made by a multidisciplinary team within an expert centre were never followed up in the community,[117] which may have resulted from the lack of a care manager who was responsible for long-term follow-up. Conversely, compliance with treatment recommendations–made after home visits by a multidisciplinary team–was much better when a Parkinson nurse followed up by telephone several weeks after the home visit.[19] Furthermore, patients in the U.S. appear to underutilize rehabilitation services, particularly when they are not followed-up by a neurologist.[29] Having access to a personal care manager could be a solution for this issue.

Research in the field of dementia has shown that the quality of care improves and that costs are reduced when patients have access to a personal care manager.[8] There is less research experience in PD, although a recent controlled study showed that persons with PD whose care was guided through the telephone by Parkinson nurses were more likely to be managed according to established quality indicators.[118] Except for an effect on depression, this care management did not translate into tangible health benefits (most patient-centred outcomes were no different from a control group receiving usual care), so more work remains to define the optimal care management profile.

Supplement D. Economic feasibility in low-income, low-middle and higher-income countries.

It is uncertain whether the approach proposed here will be economically feasible in low-income, low-middle income countries or even higher income countries. We should emphasise that the primary aim is not to save costs, but to improve the quality of care, thereby improving patient outcomes and quality of life. However, some concurrent cost savings can be expected. Prior work showed that a multidisciplinary network approach was cost-effective in the Netherlands, where the costs of building and maintaining a professional network were outweighed by subsequent cost savings, resulting from greater efficiency of care, prevented disease complications and fewer inpatient admissions.[93] While it is uncertain whether this experience can be translated to other countries, it is conceivable that even greater cost savings could arise in areas where hospitalization rates are higher than those in the Netherlands.[93] This includes the US, where many patients have no access to a neurologist, and this is associated with a higher rate of inpatient admissions.[119,120] Hence, the potential benefits of an integrated and patient-centred care system are potentially even higher in countries where care is currently les well organised compared to the Netherlands. Importantly, although we present the integrated and patient-centred care solution here to address the demands of major neurological disorders, we–and others[121,122]–feel that a comparable approach will also benefit other major societal threats, such as the burden of cancer, cardiovascular disease, and other prevalent diseases.[56]

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